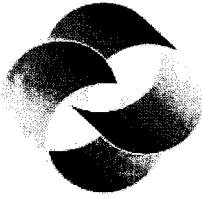


EXHIBIT 2
DATE 1-26-07
HB 278



Shodair Children's Hospital

**Psychiatric Care for Children and Adolescents
Medical Genetic Services**

Testimony and Exhibits For House Bill 278

**Submitted
On Behalf of Shodair Children's Hospital**

Case Statement for Increased State Funding of Medical Genetic Services (Presented to 2007 Montana Legislature)

1. Genetic Services are an important part of Montana's Healthcare Services

- During the 2005-2007 Biennium, 1757 Montanans have consulted with genetic professionals at Shodair Children's Hospital on inherited conditions and diseases.
- Since genetic conditions are inherited diseases, the impact of a genetics program is great on entire families and generations, not just the patients themselves.
- From 1992 through 2004, numbers of clinical genetic patients increased by 24 %. In the current biennium, the number of patients increased an additional 15%. Services for these patients were made possible by the funding provided by the 2005 legislature.
- Each year new genetic findings help physicians to diagnose and treat more medical conditions.

2. It is critical for Montanans to have access to specialized genetic services within the state.

- A physician geneticist and genetic counselor travel to over 70 clinics throughout the state each year. Monthly clinics are held in Billings, Missoula, Bozeman and Great Falls. Four to six clinics per year take place in Kalispell, Bozeman, and Butte. Cleft Palate Clinics are also held at least once a year in Wolf Point, Browning, Sidney, and Miles City.
- With telemedicine technology, patients can be seen almost immediately for emergencies or if they are unable to travel. Shodair has access to over 100 telemedicine sites throughout Montana.
- Montana healthcare professionals have access to Shodair's genetic staff 24 hours a day for consultations via a toll-free 800 number.
- If specialized Medical Genetic Services were not available in Montana, families would have to travel to Seattle, Minneapolis or Denver for services.

3. The current level of funding is critical to keeping medical genetic services accessible for Montanans.

- Medical Genetic Services are funded through a special revenue account—a fee assessed on health and disability insurance policies in Montana. From 1992 to 2005, the fee was \$.70 per year. The 2005 Legislature increased this amount to \$1.00 per year. This amount of funding is critical to meeting the increasing need for genetic services.
- Between 1992 and 2004, state-supported funding for genetic services in Montana decreased by 10% from \$554,340 in 1992, to \$500,000 in 2005. This decrease is in actual dollars and not adjusted for inflation.
- Between 1994 and 2005, The Montana Children's Foundation (a charitable foundation that raises money to support the overall operation and services of the Hospital) provided \$868,254 to ensure that patients needing medical genetic services received them.
- In 2006, Shodair received \$793,236 in funding for the Montana Medical Genetics Program through a contract with the Montana Department of Health and Human Services funded through a special revenue account. In 2007, The Hospital will receive \$793,236 through that contract.

- 4. Patients often decline needed services because they are unable to pay for them—leaving them without important healthcare information. Shodair Children's Hospital encourages all patients to be seen regardless of their ability to pay.**
- Third party reimbursement for genetic services, even when available, is often extremely limited. In 2006, reimbursement from all third party payers—including Medicare, Medicaid, and other insurance—was only 44% of billed charges.
 - Patients often forego genetic testing because of lack of Medicaid reimbursement. Medicaid does not reimburse for tests that cannot be performed in Montana and must be sent out of state to a Medicaid non-participating laboratory.
 - When patients attempt to have services pre-authorized with insurers and receive denials, they often cancel or do not keep scheduled appointments. When they are not seen after referrals, lack of diagnosis, appropriate treatment, and follow-up can cause long term health problems for patients.
 - In 2006, Shodair Children's Hospital provided more than \$15,000 in charity services for patients needing medical genetic services.
- 5. Other methods of funding have been evaluated, but are not adequate to fund the program.**
- The possibility of including self-funded plans in the special revenue account was considered at the request of several insurance companies.
 - Self-funded insurance programs are not subject to regulation by the insurance commissioner. They are exempt by Federal law (ERISA). There is no process or mechanism in place to know how many of these programs there are or how many people are insured by these programs. There is no way to collect or enforce collection of the fee from these groups.
 - For the past two years, ending June 30, 2006, the cost of providing these valuable community services exceeded reimbursement (including state funding) by over \$225,000. For the current year, services are being provided at near break even.
- 6. Genetics is part of a comprehensive system of healthcare that can save healthcare dollars by assisting in accurate, early diagnosis and treatment recommendations.**
- Staff at Shodair work with obstetricians, neonatologists, pediatricians, oncologists, internists, family practitioners and a variety of other specialists to provide a comprehensive, integrated approach to patient care.
 - Genetic counseling and testing enable healthcare professionals to identify risk for many adult onset genetic conditions including hemochromatosis. Identifying increased risk allows for early diagnosis and treatment. Equally important, early identification of reduced risk can prevent costly medical and surgical procedures.
 - Early diagnosis of the genetic condition Marfan syndrome, for example, can allow increased surveillance and treatment to prevent life-threatening heart problems.

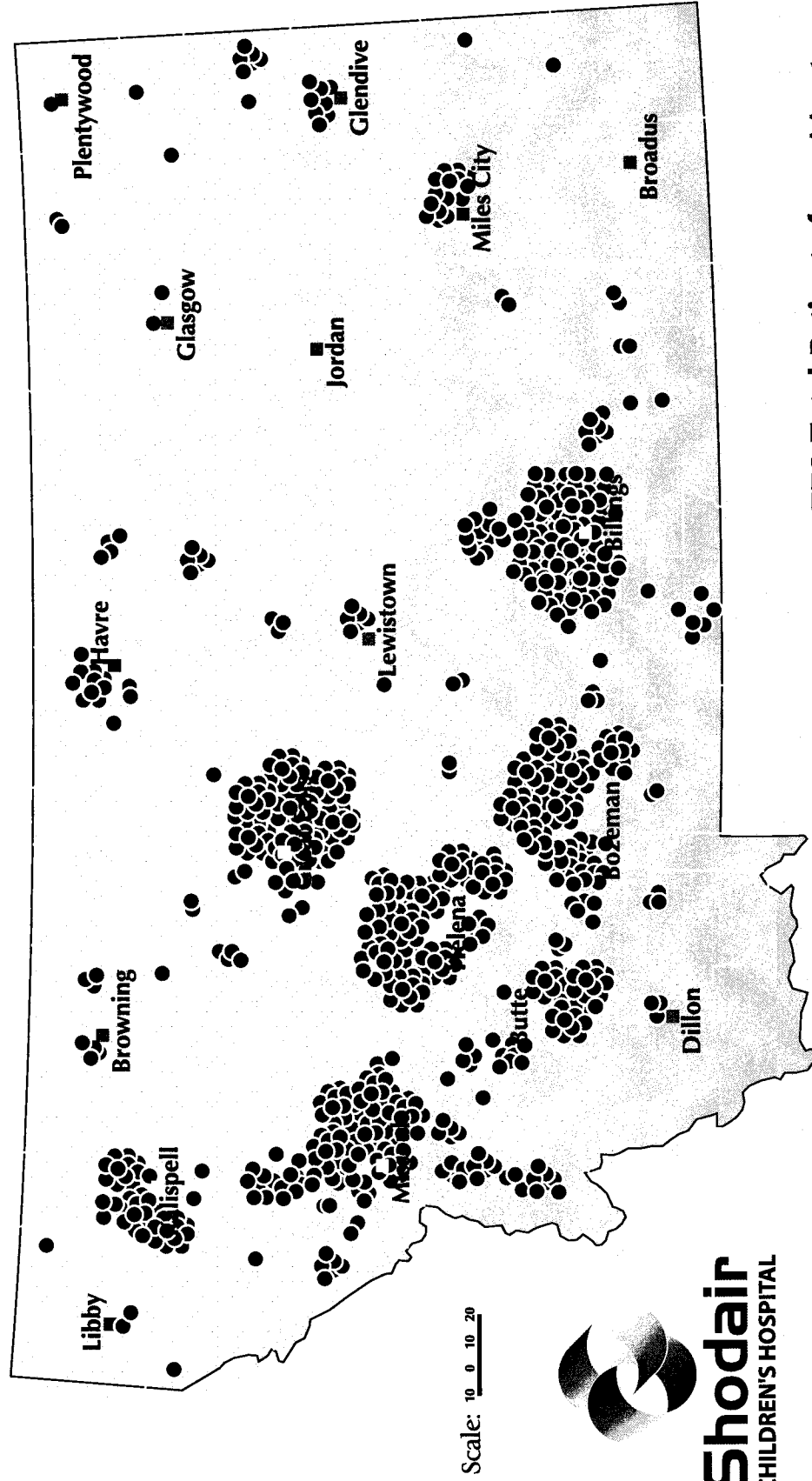
7. Genetic services provide a critical link for patients and families to other healthcare, educational, and support services.

- Shodair's genetics staff works with a network of healthcare professionals from around Montana to provide resources for patients: Speech therapists, physical and occupational therapists, support groups, and public health nurses are among the many other healthcare providers with whom Shodair staff interacts to assist patients.
- Shodair's genetic staff also works with schools—either directly or through patients' families—to help teachers understand learning disorders and other special needs of children with genetic conditions.

8. As it is throughout the nation, cancer genetics is an emerging need in Montana. Patients can now make important treatment decisions based on genetic information.

- Genetic counseling and testing enable earlier diagnosis of cancers—when they are most treatable, as well as prevention for certain types of cancers.
- Genetic characterization of leukemia and other cancer types is vital to diagnosis, prognosis, and treatment of the disease.
- Example: A specialized tissue test performed at Shodair—known as *her2neu*—identifies changes in breast cancers which respond well to the drug Herceptin. This is important, because other kinds of breast cancer do not respond to this drug, which is costly and often has major side effects for patients who take it.

Shodair Genetic Patients 2005 by Montana City



778 Total Patients from Montana

(Surrounding States 11)



Shodair
CHILDREN'S HOSPITAL

	Jun-04	Jul-04	Aug-04	Sep-04	Oct-04	Nov-04	Dec-04	Jan-05	Feb-05	Mar-05	Apr-05	May-05	FY PTS	PROFICIENCY	VALIDATION	FY TESTS
AMNIOTIC FLUID (AF)	17	19	16	23	20	13	33	21	20	21	20	18	241	5		246
LYMPHOCYTE (LC)	22	21	20	27	27	19	20	20	17	28	31	18	270	5		275
EXTENDED BANDING (EB)			2	2	1		2		1	1			9			9
TISSUE-OTHER (TC)							1				1	1	3			3
CELL CULTURE ONLY (CC)	1	1			2	2			1	1			8			8
BONE MARROW (BM)	14	10	20	21	16	19	21	15	13	20	23	25	217	5		222
ONCOLOGY BLOOD (OB)	0	2		4	1			1	3		1		12			12
CHORIONIC VILLI (CV)	5	2	2	7	6	6	8	3	5	4	7	5	60			60
FETAL HEMOGLOBIN (FH)	0												0			0
FISH (FI)	14	15	12	24	21	23	24	31	33	34	43	9	283	5	25	313
ACETYLCHOLINESTERASE (AC)	0	0	0	1	0	2	0	0	0	0	1	1	5	0	0	5
HER2/neu FISH	11	19	10	17	23	18	23	10	18	12	9	14	184	3		187
BIOCHEMISTRY (BC)					2	2							4			4
SUBTOTAL CYTO	93	96	84	130	122	110	139	112	113	130	138	95	1362	23	25	1410
FETAL PATH CHROMOSOMES (FC)	9	7	2	4	3	6	7	11	2	9	2	4	66			66
FETAL AUTOPSY	2					1							3			3
FETAL EXAM													0			0
SUBTOTAL FETAL EXAM & AUTOPSY	2	0	0	0	0	1	0	0	0	0	0	0	3	0	0	3
PRADER-WILLI METHYLATION	3	3	7	6	3	6	3	7	2	3	4	7	54	3		57
ANGELMAN METHYLATION	8	20	8	12	10	10	10	12	9	16	13	10	138		1	139
FRAGILE X TESTING	5	4	3	6	7	3	2	8	3	10	11	7	69	3		72
MYOTONIC DYSTROPHY	1	1	1	1		2		2					8	3		11
HUNTINGTON DISEASE		2				2	1	1			1	1	8	3		11
UNIPARENTAL DISOMY SCREEN	1	2	3	4	7	2	3	3	3	6	1	3	38		67	27
HEMOCHROMATOSIS	3	5	3	7	7	4	6	2	4	3	7	7	58	3		61
FACTOR V LEIDEN	2	1			2	1	3		3	1	1		14	3		17
PROTHROMBIN (FACTOR II)		1			2	1	2		4	1	1		12	3		15
MTHFR						1	2		4	1	2	2	12	3		15
LIT1 / KCNQ10T1 METHYLATION	20	24	12	19	16	15	17	14	13	25	16	24	215		1	216
X-CHROMOSOME INACTIVATION			2	5	1	2	2	1	1	3	2	5	24			24
TRISOMY SCREENING	1					1				2		1	5		2	7
GENDER SCREENING											1		1			1
LINKAGE STUDIES													0			0
MATERNAL CELL CONTAMINATION													0			0
OTHER (Triploidy parentage, zygosity)					1								1			1
SEND OUT SPECIMENS	1					5	1	5	1		4	7	24			24
DNA (DN)	45	63	39	60	56	55	52	55	47	71	64	74	681	24	71	776
DNA EXTRACTION SENT OUT	1	2	1	2	1	3	1	1				1	13			13
DNA EXTRACTION BANKED		9	9	6	3	4	4	2	3	3		2	45			45
SUBTOTAL DNA	46	74	49	68	60	62	57	58	50	74	64	77	739			739
AFAFP (AP)	18	19	16	23	20	12	32	22	18	21	15	21	237	6	0	243
MSAFP (AS)	3	4	3	1	3	5	2	7	3	2	5	4	42	0	0	42
TRIPLE SCREEN (TS)	137	135	118	118	116	141	160	126	120	152	131	111	1565	15	72	1652
QUAD SCREEN (QS)	33	27	29	38	43	47	45	51	27	34	52	37	463	15	0	478
SUBTOTAL SPECIAL CHEM	191	185	166	180	182	205	239	206	168	209	203	173	2307	36	72	2415
MEDICAL GENETICS																0
OUTPATIENTS																0
NEW																
RETURN																
INPATIENTS																
PRENATAL PHONE																
FIELD CLINIC PATIENTS																
NEW																
RETURN																

	Jun-05	Jul-05	Aug-05	Sep-05	Oct-05	Nov-05	Dec-05	Jan-06	Feb-06	Mar-06	Apr-06	May-06	FY PTS	PROFICIENCY	VALIDATION	FY TESTS
AMNIOTIC FLUID (AF)	19	19	24	16	16	20	23	25	16	19	16	38	251	5		256
LYMPHOCYTE (LC)	18	16	14	10	17	12	22	21	25	29	20	20	224	7	3	234
EXTENDED BANDING (EB)													0			0
TISSUE-OTHER (TC)			1										1		1	2
CELL CULTURE ONLY (CC)			1	1	1		1						4			4
BONE MARROW (BM)	24	22	23	21	22	21	31	26	20	19	16	16	261	10		271
ONCOLOGY BLOOD (OB)	1	1	3	1		2	2	1	2		1		14			14
CHORIONIC VILLI (CV)	5	5	7	4	3	3	5	1	3	10	6	5	57			57
FETAL HEMOGLOBIN (FH)													0			0
FISH (FI)	16	20	30	17	26	20	23	40	28	29	29	30	308	9	68	385
ACETYLCHOLINESTERASE (AC)	2			1		1							4			4
HER2/neu FISH	10	10	8	19	9	9	8	11	21	16	11	11	143	2		145
BIOCHEMISTRY (BC)													0			0
SUBTOTAL CYTO	105	102	115	97	102	92	118	127	119	127	105	123	1332	35	72	1439
FETAL PATH CHROMS (FC)	10	9	4	7	8	4	3	2	4	5	6	3	65	2		67
FETAL AUTOPSY													0			0
FETAL EXAM													0			0
SUBTOTAL FETAL EXAM & AUTO	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PRADER-WILLI METHYLATION	7	2	5	5	7	7	3	3		6	2	3	50	3		53
ANGELMAN METHYLATION	13	16	21	12	19	11	12	11	8	17	7	7	154			154
FRAGILE X TESTING	7	5	5	3	7	2	3	6	11	7	5	3	64	3		67
MYOTONIC DYSTROPHY			1									2	3		3	6
HUNTINGTON DISEASE			1	1		1	1	1	1				6		3	9
UNIPARENTAL DISOMY	7	4	4	4	2	2	2	5	4	4	3	3	44		77	121
HEMOCHROMATOSIS	6	3	3	10	6	4	4	10	9	13	1	5	74	3		77
FACTOR V LEIDEN	2	3		3			3		3	3	1	1	19	3		22
PROTHROMBIN (FACTOR II)	1	3	1	4			3	1	3	2	1	1	20	3		23
MTHFR	1	3		3			3	1	2	2	1	1	17	3		20
LIT1 / KCNQ10T1 METHYLATION	15	19	25	11	21	11	17	11	12	17	13	17	189			189
X-CHROMOSOME INACTIVATION	3	3	3	2	1	1		4	1	3	3		24			24
TRISOMY SCREENING			1										1			1
GENDER SCREENING													0			0
LINKAGE STUDIES													0			0
MATERNAL CELL CONTAM										1			1		1	2
OTHER (Triploidy, zygosity)			2			1		1	1		1		6		5	11
SEND OUT SPECIMENS	5	1	4	4	5	4	4	7	2	11	4	5	56			56
DNA (DN)	67	62	76	62	68	44	55	61	57	86	42	48	728	18	89	835
DNA EXTRACTION SENT OUT				1	1	2		4				1	9			9
DNA EXTRACTION BANKED	1		6		5	6	3	3		3	1	7	35			35
SUBTOTAL DNA	68	62	82	63	74	52	58	68	57	89	43	56	772	0		772
AFAFP (AP)	12	17	24	18	16	18	20	29	16	18	16	36	240	6		246
MSAFP (AS)	6	2	6	4	3	5	4	8	7	3	6	8	62	0		62
TRIPLE SCREEN (TS)	146	98	116	118	97	112	104	143	126	125	108	98	1391	15	36	1442
QUAD SCREEN (QS)	50	47	32	47	41	53	51	66	45	45	49	67	593	15		608
SUBTOTAL SPECIAL CHEM	214	164	178	187	157	188	179	246	194	191	179	209	2286	36	36	2358
MEDICAL GENETICS																0
OUTPATIENTS																0
NEW																
RETURN																
INPATIENTS																
PRENATAL PHONE																
FIELD CLINIC PATIENTS																
NEW																
RETURN																
SUBTOTAL MEDICAL GENETICS	86	56	63	94	86	74	74	55	97	78	78	45	78		45	1009

January 11, 2007

Dear Members of the House Human Services Committee,

I am a science teacher at Capital High School in Helena. I am writing to ask your support of HB 278 to provide continued funding for Montana's Medical Genetics Program. Shodair provides medical genetic services for all of Montana through a contract with the Department of Public Health and Human Services.

Each year, my senior students participate in a tour and education program on genetics at Shodair Children's Hospital. Montana is incredibly fortunate to have a high quality genetics program located within the state. My students come away from their experience at Shodair with an appreciation for how important genetics is in health care. They also have a heightened interest in science related careers.

I also have some personal experience as a patient with Shodair's genetic services. My son and I are both unusually tall, and experience some vision problems. These symptoms can be an indication of a genetic condition called Marfan Syndrome. The really scary thing about Marfan Syndrome is that it also carries serious heart defect that can cause sudden death. My son and I worked with Dr. John Johnson and Katherine Berry, a genetic counselor at the program to determine that we do not have this condition. You can imagine our relief.

It's important for Montanans to have these services available within the state. I urge your continued support for funding for this program.

Sincerely,

A handwritten signature in cursive script that reads "Tom Pedersen". The signature is written in dark ink and is positioned below the word "Sincerely,".

Tom Pedersen
Capital High School

January 11, 2007

Members of the House Human Services Committee,

My name is Kelly Chapman. I live in Helena. I am writing to ask your support of HB 278 to provide continued funding for Montana's medical Genetics Program.

My mom has ovarian cancer. I became concerned about my risk for cancer, and that of my children. I contacted the Medical Genetics program at Shodair Children's Hospital. Shodair is the home to Montana's Medical Genetics Program.

I worked with a counselor, Katherine Berry, and physician, Dr. John Johnson to understand the inherited risk of cancers such as ovarian and breast cancer. It turned out that my mother's cancer carries strong inheritance risk. I'm happy to report that my tests showed that I did not carry the gene for inheritance of this cancer. That was great news for both me and my three children.

It also means that I won't be subjected to more frequent and costly mammograms and other cancer screenings.

I am grateful that Medical Genetic Services can be offered in Montana. The Services provided by Shodair have given me peace of mind, and have saved healthcare dollars.

I urge you to support continued funding of this program.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kelly Chapman', followed by a long horizontal line.

Kelly Chapman

January 1, 2007

Members of the House Human Services Committee

My son, Hunter Peterson is fifteen. He is developmentally delayed, has seizures, and since he was an infant, has suffered from chronic constipation and diarrhea.

We've been to specialists all of Hunter's life without getting a definitive diagnosis, or help for his condition. As a result, Hunter has had significant problems in school with toileting issues.

Finally, in April of 2005, we were referred to a genetics clinic provided by Shodair Children's Hospital and funded through the Montana Department of Public Health and Human Services.

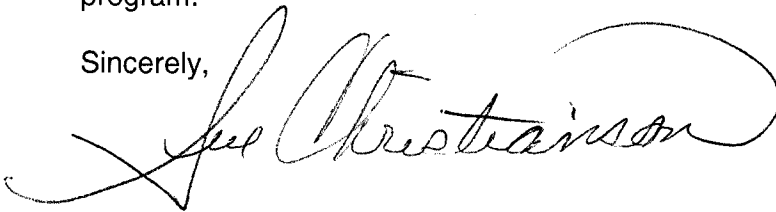
The physician and counselor met with us and recommended chromosome testing for Hunter. Dr. Jim Reynolds, a medical geneticist was able to diagnose Mowat-Wilson syndrome, a very rare genetic condition which causes developmental delay, small head size, seizures, and bowel problems. Hunter's constipation and diarrhea are caused because part of his colon has no nerve endings.

I can't tell you how this information has changed our lives. For the first time since Hunter's birth, we have answers. I no longer feel guilty for somehow causing his problems. I am better able to help him, and we are managing his diarrhea and constipation with diet and medication.

Hunter and I feel very fortunate to have the availability of these specialized medical services in Montana. They have truly changed our lives.

I ask you to vote in favor of House Bill 278 to continue the level of funding for this program.

Sincerely,

A handwritten signature in cursive script, reading "Sue Christianson". The signature is written in dark ink and is positioned above the printed name.

Sue Christianson
Missoula

January 22, 2007

Representative Ron Stoker
P.O. Box 201706
Helena, MT 59620-1706

RE: House Bill 278

Dear Representative Stoker:

I am writing on behalf of the State of Montana, Department of Justice, Forensic Science Division Laboratory in support of House Bill 278 "an act setting the Genetics Program Fee.." As you are aware, part of the charge of the Forensic Science Division Laboratory is to assist the coroners in the State of Montana to determine the cause and manner of death. On some occasions when the cause of death has potential implications for surviving family members it is very beneficial for our pathologists to be able to refer these families to Shodair Children's Hospital for their assistance and expertise with genetic issues.

The ability for Shodair to continue research and consultation services is vital to the improvement of medical genetic services for the people of Montana.

This letter strongly supports passage of HB 278 that will provide on-going funding for these specialized services. If I can be of any assistance please feel free to contact me.

Sincerely,

Bill Unger
Administrator
Forensic Science Division

January 1, 2007

Members of the House Human Services Committee

I am writing to ask your support of House Bill 278 to provide continued funding for Montana's medical Genetics Program. The program has provided valuable, and potentially life saving information for my family.

My Grandmother, mother, and daughter have had breast cancer. Two of my brothers were diagnosed with breast cancer while they were in their fifties. I have children and I was concerned about their risk for breast cancer.

I was able to see the counselor and physician from Shodair's Medical Genetics Program right here in my hometown of Missoula. With counseling about risk for breast cancer and testing, I found out a month later that I do indeed carry the same mutation as other family members with breast cancer. Because of this genetic testing result, I am about 120 times more likely to develop breast cancer than the average male. I will now start having annual mammograms for early detection.

More important to me is the vital information that Shodair has provided me for my children. I have eight children all of whom are at potential risk for breast and ovarian cancer. They can now make decisions to be tested and implement early detection measures themselves.

Availability of genetic services within Montana is vitally important to my family's health. I am grateful for their expertise.

I urge you to support continued funding of this program.

Sincerely,

A handwritten signature in cursive script that reads "Bill Sayen".

Bill Sayen
Missoula

January 21, 2007

To Whom it May Concern,

Mr. Chairman, Members of the Committee:

My name is Jade Carter, I am a Montana native, born in Billings. I spent a good share of my childhood suffering from strange symptoms that no doctor could seem to put a name on. By the time I was in my early teens, I had developed excruciating headaches that could not be controlled by regular pain-relievers or even prescribed medications. My mother suffered the exact same symptoms as me; she too went undiagnosed, or misdiagnosed all her life. When I was 15, my mother was diagnosed with a disease called Chiari [Brain] Malformation. It was then that we began to wonder if I had the same thing...

My health grew worse, and my High School, Skyview, put me on their "handicapped" list, even though we still had no diagnosis. My grades began to drop, I was missing so much school; falling down, blacking out, I could not even think my head hurt so bad.

I went to so many doctors, they could find nothing wrong with me. Finally, in Oct. of 2003, one of our local Neurologists, considered the top of his field, diagnosed me as needing Psychiatric treatment. We knew that wasn't the case, but no one would even listen. Finally we were put in touch with Shodair Childrens Hospital in Helena, and directed to their Genetics Department. Those folks knew what Chiari was, and that it wasn't a "psychiatric" problem. They sent a team of specialists down to meet us, as traveling is a nightmare for us. We met Dr. Reynolds, a Medical Geneticist, and Cindy Hudson, a Genetic Counselor at a clinic in Billings in Nov. 2003. They asked a lot of questions, and came to the conclusion that I needed to see a specialist. They assisted us in getting to a team of experts in New York, and are we glad we listened to them!

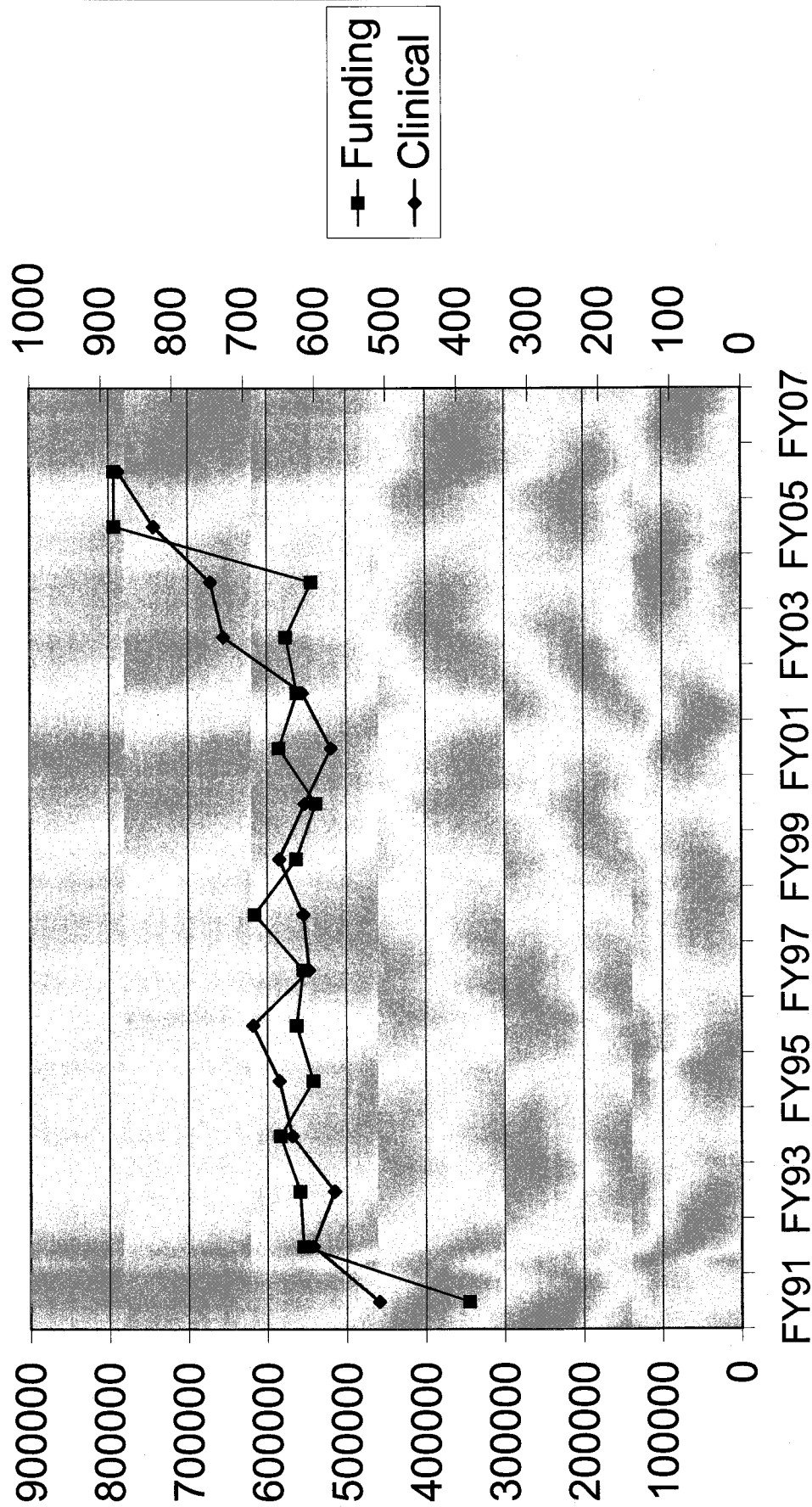
As it turns out, I did have a Chiari Malformation, but one that was hard to detect without a diagnostic tool called Cine MRI; this was not available in MT at that time. When you have Chiari, your Cerebellum is too large for your skull, and the brain presses into the brain-stem and spinal cord, causing blockage of the CSF, Cerebrospinal Fluid. I was getting no fluid to my brain, and this pressure caused a condition known as Syringomyelia, cysts in my spinal cord, to form. I underwent a brain decompression and laminectomy of the C-1 vertebrae in April of 2004; but yet another surprise was to follow. After my brain surgery, the doctors in N.Y. found I also had another condition called Ehler-Danlos Syndrome. This is an anomaly of the tendons, ligaments and dura, so then I had to have a Craniocervical Fusion, my skull is rodged to my neck. I do feel much better, and I am living a much more normal and active life. I don't know where I would be if the Shodair Genetics team had not stepped into my life... The Genetics staff at Shodair helped save my life, and many other kids in MT. For people like me with Genetic disorders and diseases that are considered rare, they provide diagnosis, support, resources and hope. I strongly urge you to support House Bill 278, to support the existing funding for Montana's Medical Genetics services. We would be lost without them.

Sincerely,



Jade Michel Carter, age 20

Genetics Volume and Funding



Genetic Laboratory and Clinical Volume

